Moral distress within neonatal and paediatric intensive care units: a systematic review

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ABSTRACT

Objective To review the literature on moral distress experienced by nursing and medical professionals within neonatal intensive care units (NICUs) and paediatric intensive care units (PICUs).

Design Pubmed, EBSCO (Academic Search Complete, CINAHL and Medline) and Scopus were searched using the terms neonat*, infant*, pediatric*, prematur* or preterm AND (moral distress OR moral responsibility OR moral dilemma OR conscience OR ethical confrontation) AND intensive care.

Results 13 studies on moral distress published between January 1985 and March 2015 met our inclusion criteria. Fewer than half of those studies (6) were multidisciplinary, with a predominance of nursing staff responses across all studies. The most common themes identified were overly 'burdensome' and disproportionate use of technology perceived not to be in a patient's best interest, and powerlessness to act. Concepts of moral distress are expressed differently within nursing and medical literature. In nursing literature, nurses are often portrayed as victims, with physicians seen as the perpetrators instigating 'aggressive care'. Within medical literature moral distress is described in terms of dilemmas or ethical confrontations.

Conclusions Moral distress affects the care of patients in the NICU and PICU. Empirical data on multidisciplinary populations remain sparse, with inconsistent definitions and predominantly small sample sizes limiting generalisability of studies. Longitudinal data reflecting the views of all stakeholders, including parents, are required.

What is already known on this topic

► Most studies on moral distress focus on nurses in adult settings.
► Moral distress affects personal well-being, job retention and patient outcomes.

What this study adds

► Moral distress appears to affect care in neonatal and paediatric settings.
► However empirical data on moral distress are sparse in these services.
► More extensive and longitudinal data on moral distress in these settings are needed.

INTRODUCTION

Moral distress refers to the anguish experienced when an individual makes a clear moral judgement about what action he/she should take but is unable to act accordingly due to constraints (societal, institutional or contextual). This is the 'essence' of Jameton's original definition.[1] Moral residue refers to the lingering feelings that remain once the morally distressing situation has passed.[2] In the adult nursing setting, moral distress has been implicated in compromising personal integrity,[3–5] creating dissatisfaction within the workplace environment,[4] contributing to burnout of staff[6] and ultimately having a negative impact on patient care. Neonatal intensive care units (NICUs) and paediatric intensive care units (PICUs) are high-pressure environments where technology creates potential for burdensome care with limited perceived benefits in vulnerable populations, such as described in the fictional cases of Kevin and Mary in this paper. It is thus reasonable to expect that significant moral distress may exist in these settings. However, there is limited evidence on moral distress within neonatal and paediatric healthcare professionals.[4 7] This systematic review first seeks to examine the empirical research that exists about the nature and degree of moral distress experienced within NICUs or PICUs. This is useful in documenting how moral distress is represented differently within different healthcare professionals. Following this, the paper raises questions about the nature of moral distress, who feels it and its ethical significance.

METHODS

The review was conducted using PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines.[8]

Search strategy

An electronic literature search of Pubmed, EBSCO (Academic Search Complete, CINAHL and Medline) and Scopus was performed using combinations and spelling variations of the following key words: neonat*, infant*, pediatric*, prematur* or preterm AND (moral distress OR moral responsibility OR moral dilemma OR conscience OR ethical confrontation) AND intensive care. The last search was conducted on 1 April 2015. Reference lists of papers that underwent full-text analysis were scanned for additional studies. Furthermore, references from review articles on moral distress were scanned for eligible studies. The first author (TP) formulated the search terms and conducted the electronic search. The results from the different

Case 1

Kevin, a preterm baby born at 23 weeks gestation, develops severe necrotising enterocolitis at 2 weeks of age. Additionally, Kevin has severe lung disease and is dependent on a ventilator for survival. He is taken to theatre where the surgeons declare that there is no viable gut left. Despite being informed of the poor prognosis, the parents refuse the recommendation for redirection of care to comfort care.

Case 2

Mary, a 2-year-old child, suffers profound hypoxic ischaemic encephalopathy after near-drowning. Both the brain MRI and clinical examination are consistent with an extensive brain injury that will result in profound disability should she survive. Additionally, Mary is suffering from multiorgan failure, including renal failure, due to the significant hypoxic insult. The medical team have counselled the family that redirection to comfort care is in Mary's best interest, due to the extensive brain and kidney damage. The parents are initially in agreement. However shortly after a nephrology consultant speaks to them about dialysis, they change their mind and want to continue 'full active management' for their daughter.

Figure 1 Literature review process.

databases were merged and duplicates removed. Argument-based literature, editorials, commentaries, dissertations, letters and opinion pieces were excluded. Articles were limited to those published after 1984—the year the term 'moral distress' was first coined by Jameton.[1] Studies were limited to those performed in an industrialised country setting and written in English. The term moral distress carries multiple meanings, is applied predominantly in nursing literature and is often conflated with other terms such as 'moral dilemma'. The authors were therefore careful to avoid inadvertently excluding articles based on titles alone where the concept of moral distress was expressed throughout the article. A large number of key words were therefore used, but only articles on the specific topic of moral distress, using the definition used in the introduction, were analysed. Articles were additionally limited to the perspectives of healthcare providers. Intervention studies to address moral distress were also excluded from the primary analysis as they assumed a particular framework of moral distress and did not add to knowledge on the nature or intensity of moral distress. Institutional reviews were excluded if there were insufficient details to enable subanalysis of paediatric or neonatal cohorts. The last author (PGD) reviewed the search strategy, the abstracts and full text articles. Where there was doubt over the inclusion/exclusion of an article, all authors discussed the issues until consensus was reached.

RESULTS

Two authors (TP and PGD) reviewed 26 full text articles. Of these, 13 met the inclusion criteria (see figure 1). A number of institutional reviews which included data from NICUs and PICUs were excluded where subanalysis of these groups was not provided. This included one of the largest studies by Whitehead et al,[9] who interviewed 592 healthcare professionals from one large centre in the USA. Moral distress was present in all professionals with the greatest distress present in those involved in direct patient care. Given the limited number of studies, articles were not excluded on the basis of quality alone; however, the Critical Appraisal Skills Programme (CASP)[10] was used to review the quality of the included studies.
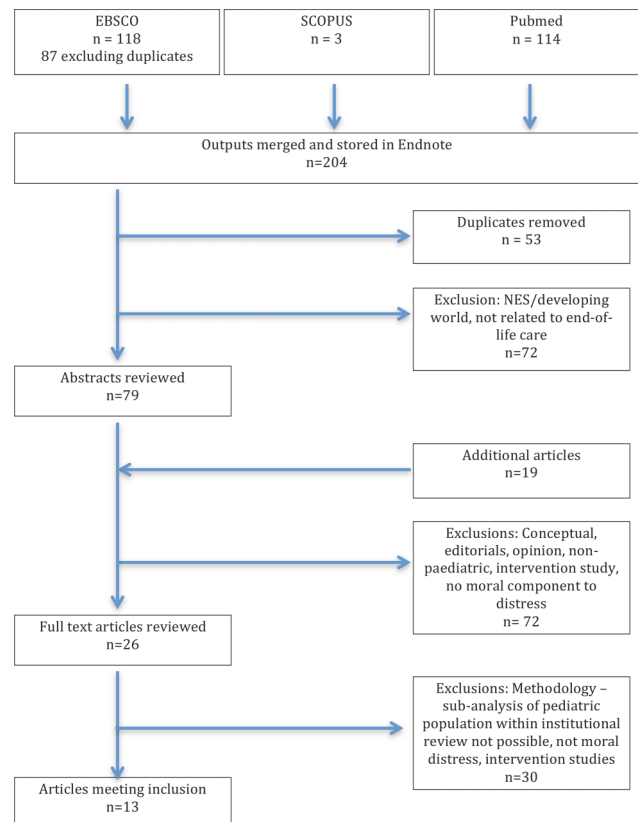
Methodological characteristics of studies

The methodological characteristics and findings are summarised in table 1.

Six of the studies were multidisciplinary (involving at least two professions, including one study surveying medical students). Nursing is the most represented profession, reflecting the origins of moral distress theory as well as the relatively high ratio of nursing staff to other health professionals within a healthcare team. Five studies had a sample size of fewer than 30 interviews. Two of the included studies were secondary analyses where the initial surveys or focus groups did not set out to address moral distress, potentially limiting their scope. Five of the studies used a version of Corley's Moral Distress Scale (MDS).

Common themes represented included disproportionate care, 'aggressive' use of technology, powerlessness, and communication around life and death issues. Interestingly, moral distress is generally reported as occurring because a provider feels she/he is 'doing too much', as illustrated by the cases of Kevin and Mary. The converse is rarely reported as causing moral distress, for example, deciding for palliative care in the face of uncertainty. Concepts of moral distress are expressed differently within nursing and medical literature. In nursing literature, emphasis was often placed on the emotional or psychological component of moral distress. Nurses express a 'voicelessness' and 'powerlessness' within the constraints of the medical hierarchy. In contrast moral distress is described in terms of dilemmas or ethical confrontations within medical literature, considering questions such as: How, and by whom should decisions be made for children like Kevin and Mary? When is death more favourable than disability? How should these considerations be communicated to parents? More recently literature has examined the ethical climate of the unit and the interactions of

Table 1 Included articles in the systematic review (ordered by date)

Author	Country	Target participants	No.	Methodology	Aims	Outcomes	Themes	Limitations	Recommendations
Hefferman et al[14]	USA	NICU staff ▶ Nurses—initial survey ▶ Nurses—second survey ▶ Neonatologists ▶ Respiratory care supervisor ▶ Advanced practice nurses (Level III NICU)	98 24 67 3 1 3	Two qualitative surveys—convenience sample—spaced two months apart	▶ To explore ethical dilemmas healthcare professionals faced and describe the impact, if any, such dilemmas had on their care or sense of self as healthcare providers ▶ Explore whether dilemmas elicit moral distress	▶ Expressed moral distress raises more questions regarding resuscitation and treatment of infants born at 'edge of viability' ▶ Difficult dilemmas can bring about moral distress in healthcare professionals	▶ Advancing technology ▶ Disproportionate care ▶ Medical hierarchy ▶ Decision-making	▶ Survey sought 'ethical dilemmas' and the term was used interchangeably with moral distress ▶ Initial survey results made available to all staff prior to second survey ▶ Unknown response rate ▶ Unclear aims and methodology	Those experiencing moral distress need to 'be given a voice' in the decision-making process
Solomon et al[11]	USA	Multidisciplinary paediatric staff in PICUs, medical, surgical or haematology/oncology units. Overall response rate 64% (54%–71% across sites) ▶ attending physicians – PICU attending physicians ▶ 'house officers' ▶ nurses – PICU nurses (3 Children's hospitals and 4 general hospitals with PICUs)	781 209 25 116 456 267	▶ Quantitative questionnaire, population based ▶ Based on the Decisions Near the End of Life Institutional profile	▶ To determine the extent to which a variety of healthcare professionals are in agreement with one another and with published ethical recommendations regarding the withholding and withdrawing of life-sustaining therapies and the role of parents in end-of-life decision-making ▶ To determine the extent to which healthcare professionals are concerned with problems of overtreatment	▶ 80% of critical care physicians and 69% of critical care nurses reported acting against their conscience and 'saving children who should not be saved' ▶ 56% of critical care physicians and 32% of critical care nurses reported feeling that sometimes the treatment they offer children is overly burdensome	▶ Conscience ▶ Burdensome care	▶ 64% response rate ▶ Did not have a probability-based sample of institutions ▶ Healthcare professionals working solely in neonates were excluded	▶ More research on regard for the dead-donor rule ▶ More ethics education required ▶ More interdisciplinary and cross-subspecialty discussion of inherently complex and stressful paediatric end-of-life cases
Janvier et al[12]	Canada	▶ Nurses, ▶ Residents (University centre, high-risk obstetric service, maternity hospital NICU, outborn NICU)	115 164	Quantitative questionnaire, population based	To determine the frequency of ethical confrontations (using a moral distress definition explicitly described) and factors associated with increased frequency	▶ Moral distress was experienced by 35% of nurses and 19% of residents ▶ Ethical confrontations are influenced by knowledge levels regarding outcomes of preterm infants (more moral distress when inaccurate knowledge) ▶ Ethical confrontations are more frequent where there is more cultural diversity.	▶ Ethical confrontations ▶ Knowledge	▶ Attending physicians not included ▶ Limited definition of ethical confrontations ▶ Only examined overtreatment and not undertreatment component of moral distress	▶ Ethical confrontation may be unavoidable and beneficial when approached critically and discussed as a team ▶ Further studies to equip trainees and healthcare workers with the tools to examine confrontations, to learn from, and profit from them

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Table 1 Continued

Author	Country	Target participants	No.	Methodology	Aims	Outcomes	Themes	Limitations	Recommendations
Catlin et al[27]	USA	Critical care nurses ▶ Neonatal ▶ Paediatric	66 53 13	▶ Pilot ▶ Mixed methods, convenience sample ▶ Multiple choice and open-ended surveys	To verify the clinical use of their concept of conscientious objection in cases of moral distress	Analysis of conscientious objection use in neonatal and paediatric nursing care	▶ Ambivalence towards technology ▶ Futility ▶ Powerlessness ▶ Fear of consequences	▶ Defining conscientious objection ▶ Is conscientious objection merely voicing a difference of opinion or refusing to follow through?	To direct research towards interventions 'that will prevent futile care as well as to protect and defend nurses from the pain of powerless and participation in such cases that appear to harming patients'
Lee and Dupree[18]	USA	PICU staff (multidisciplinary) (Single centre PICU)	29	▶ Qualitative descriptive study, population based ▶ Semi-structured interviews	To describe the experiences of PICU healthcare professionals caring for a child who dies and to determine whether healthcare professionals experienced moral distress	Grief was more prominent as a response than moral distress	▶ Communication ▶ Accommodating wishes of others ▶ Ambiguity about technology use ▶ Grief ▶ Emotional support	▶ Interviewed until saturation of themes but small sample of 8 patients ▶ Enrolled after deaths; ? appropriate timing ▶ Greater moral distress associated with patients that are thought to have received disproportionate care	▶ Communication; interventions to improve availability of physicians to parents ▶ Emotional support for staff
Cavaliere et al[4]	USA	RNs n=196 (48% response rate) (2 level III NICUs)	94	▶ Quantitative, descriptive, correlational study, convenience sample ▶ MDSNPV (Moral distress scale—paediatric version)	To describe moral distress of RNs working in NICUs and to identify the situations associated with their moral distress	▶ Moral distress, as identified by MDS was infrequent and low intensity ▶ Mean intensity scores for top 10 distressing situations ranged from 1.71 to 3.18 ▶ Following family wishes to continue when not in child's best interest caused greatest moral distress	▶ Continuing at family's wishes despite not 'best interest' of patient ▶ Powerlessness	▶ Analysis limited to items within MDS ▶ Homogenous demographics of nursing staff	▶ More studies required using the MDSNPV to refine tool ▶ Exploration of more heterogenous populations to aid generalisability
McGibbon et al[15]	Canada	PICU nurses (Paediatric hospital)	23	▶ Qualitative study, theoretical sampling ▶ Institutional ethnography ▶ In-depth interviews, participant observation and focus groups	To reformulate the nature of stress in nursing with attention to contextual aspects of nursing	▶ Nurses' stress is very much related to the social relations of power which may lead to moral distress ▶ Formulations of nursing stress (including moral distress) must reflect the dynamics between the nurse, the environment and surrounding relationships and hierarchies	▶ Emotional distress ▶ Burden of responsibility ▶ Constancy of presence ▶ Bodily caring? ▶ Being mothers, sisters, daughters and aunts	Convenience sample rather than reaching saturation of themes	Conceptualisations of nurse' stress including occupational, moral distress and traumatisation require further contextualisation
Lawrence[21]	USA	RNs n=98 (14% response rate) ▶ NICU n=90 (8%) ▶ PICU n=62 (18%) ▶ MICU n=46 (22%) (3 ICUs)	28 7 11 10	▶ Quantitative, descriptive, correlation study, convenience sample ▶ Demographic Data Collection Tool ▶ UWES ▶ MDS (in part) ▶ CRPQ ▶ RRQ in part	To examine how nurses' moral distress, education level and CRP related to work engagement	▶ Negative direct relationship between moral distress and CRP. Positive direct relationship between CRP and work engagement ▶ An increase in RN education is associated with increase CRP (in NICU)	▶ Education ▶ Workplace engagement ▶ Moral distress ▶ CRP	▶ 14% response rate ▶ Convenience sample ▶ CRPQ not standardised ▶ Only the 'not in the best interest' frequency subscale (7 items) was used limiting the scope of MD examined	▶ Strategies to promote CRP and reduce moral distress are recommended, to promote work engagement ▶ Further studies required on the role of education in nurses' work engagement recommend

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Table 1 Continued

Author	Country	Target participants	No.	Methodology	Aims	Outcomes	Themes	Limitations	Recommendations
Sannino et al[17]	Italy	Nurses n=472 (86% response rate) (15 level III NICUs)	406	▶ Quantitative, cross-sectional questionnaires, convenience sample ▶ MDSNPV-Italia	▶ To evaluate the frequency, intensity and level of moral distress experienced by nurses working in NICUs ▶ To assess whether nurses working in NICUs with >/=1000 deliveries/year experience a higher frequency, intensity and level of moral distress than nurses working in NICUs <1000 deliveries	▶ Low moral distress rate as measured by MDS. Initiating care when felt futile ranked highest cause of moral distress ▶ No association between the number of deliveries in a centre and the moral distress of nurses	▶ 'Aggressive' use of technology without perceived benefit ▶ Honouring parental decision-making	Sample limited to Northern Italy	Further studies required in neonatal context
Molloy et al[16]	Canada	Nurses (Tertiary academic referral hospital)	15	▶ Qualitative interviews, convenience sample ▶ Secondary analysis of data	To increase understanding of moral distress experienced by nurses involved in the decision-making regarding resuscitation of neonates at the margins of viability (<25+6 weeks)	Nurses perceive a lack of power and influence in the neonatal resuscitation decision-making process	▶ 5 themes contribute to moral distress – Uncertainty – Questioning informed consent – Differing perspectives – Harm and suffering – Being with the family	▶ Secondary analysis- analysis limited to original data ▶ Only 15 respondents	▶ Provide staff with coping mechanisms ▶ Engage more effective communication strategies ▶ Additional research on why nurses feel helpless in decision-making
Sauerland et al[7] (Part II)	USA	Nurses working in NICU/PICU and intermediate care settings n=152 (35% response rate) (Academic safety net hospital—provides significant service to lower socioeconomic population)	53	▶ Quantitative questionnaires, convenience sample ▶ MDSNPV ▶ Olson's HECS-S	To explore perceptions of moral distress, moral residue and ethical climate among registered nurses	▶ PICU and NICU nurses experience less moral distress than those in adult ICUs ▶ Greatest distress caused by inadequate staffing, incompetent staff, performing unnecessary tests and treatments and continuing life support when not in child's best interest ▶ Work climate was ranked as moderately ethical	▶ Work climate ▶ Moral distress	▶ 35% response rate ▶ Single site ▶ Lack of differentiation between NICU/PICU nurses and involvement in critical care vs intermediate setting	Intervention studies that address moral distress at the individual, intraprofessional/ interprofessional environment and hospital policies
Trotochaud et al[19]	USA	Multidisciplinary paediatric healthcare providers ▶ NICU nurses ▶ NICU other ▶ PICU nurses ▶ PICU other Overall response rate ranged from 26.3% for physicians across all	1113 84 38 79 47	▶ Quantitative descriptive study, convenience sample ▶ MDS-R ▶ Survey questions on demographic and intent	▶ To determine the degree of moral distress experienced by paediatric providers from different professional groups and working in different clinical settings ▶ To describe the relationship of moral distress to paediatric provider intent to leave	▶ Both physicians and nurses experience moral distress (percentage, describe) ▶ 'Aggressive' burdensome end-of-life care not considered appropriate is commonly associated with moral distress	▶ Moral distress ▶ 'Aggressive treatment' ▶ Teamwork	▶ <30% response rate across all paediatric and neonatal professionals ▶ Responses from single organisation	Strategies that help providers recognise morally distressing situations when experienced

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Table 1 Continued

Author	Country	Target participants	No.	Methodology	Aims	Outcomes	Themes	Limitations	Recommendations
		departments to 40.9% for nurses across all departments (3 Children's hospitals)			▲ To identify situations more likely to be associated with paediatric provider moral distress				
Wall et al[20]	Canada	Multidisciplinary: ▲ dieticians, ▲ respiratory therapist ▲ social worker ▲ nurses, ▲ physicians, ▲ medical resident (multicentre PICUs)	16 3 1 1 7 3 1	▲ Qualitative interviews and focus groups, convenience sample ▲ Secondary analysis	To explore organisational influences on moral distress for healthcare professionals working in PICUs	Individual experience, ethical climate and organisational structures are intertwined in creating moral distress	▲ Relationships with management, organisational structure and processes ▲ Workload and resources ▲ Team dynamics	▲ Small sample size with limited generalisability. ▲ Secondary analysis— moral distress was not a focus of the original interview questions	Further exploration of the impact of organisational structures on moral distress is required

CRP, critical reflective practice; CRPQ, critical reflective practice questionnaire; HECS-S, hospital ethical climate survey; ICU, intensive care unit; MDS, moral distress scale; MDS-R, moral distress scale revised; MICU, medical intensive care unit; MDSNPV, moral distress scale neonatal-paediatric version; NICU, neonatal intensive care unit; PICU, paediatric intensive care unit; RN, registered nurse; RRQ, reflection-rumination questionnaire; UWES, Utrecht work engagement scale.

various healthcare professionals within the organisational structures, rather than focusing on the individual experiences of a particular healthcare professional. Such studies into ethical climate were in the minority.

DISCUSSION

In common with the adult nursing literature, moral distress within NICUs and PICUs most commonly results from disproportionate interventions perceived to not be in the child's best interests,[11 17 19] often within a negative ethical climate. With an increasing reliance on life-sustaining technology within intensive care, moral distress is a significant issue for healthcare professionals working in these environments. However, research has been hindered by unclear definitions of the term, small sample sizes and poorly designed studies that frequently lack a multidisciplinary approach.

Despite the large amount of theoretical and increasing empirical literature (especially in adult nursing literature) the term moral distress is not commonly used in clinical practice, making empirical research and direct enquiry difficult. Janvier et al[12] instead use the term 'ethical confrontations'. While this term captures the moral component and suggests some form of disagreement, the term may be too broad, encompassing moral *dilemmas*. At times the difference between moral distress and moral dilemmas may be subtle, but it is important. In moral dilemmas, there are competing ethical principles, but no single principle clearly outweighs any another in that situation. This can create distress related to uncertainty about the right course of action. By contrast, in moral distress characteristically the right course of action is clear, but there are barriers or constraints which prevent healthcare professionals from taking this course of action. Moral distress therefore challenges personal moral integrity, resulting in the negative consequences to self and patient care. Hefferman and Heilig[19] specifically sought responses about moral dilemmas, yet many of their examples are of moral distress, demonstrating the terms have been conflated. Lee and Dupree[14] have used a much more stringent definition of moral distress, whereby cases must demonstrate an external constraint impacting action and the 'right' action not being taken. Additionally, their study sought unprompted expressions of moral distress to prevent measurement bias, using content analysis of staff experiences surrounding the death of critically ill patients. The study is useful in describing that not all distress surrounding the death of a child is moral distress, and such emotions can be an important expression of humanity. Common terms and framing of moral distress within different healthcare settings will strengthen a meaningful discussion and collaboration between disciplines.

Three themes featured commonly within the literature: causes of moral distress, relational dynamics between healthcare professionals within different settings or ethical climate and the impact of moral distress over time. The primary causes of moral distress in these studies were perceived disproportionate care, considered not in a patient's best interests and a perceived inability on the part of the healthcare professional to advocate for the child. The advancement of technology per se was often a source of ambivalence among (particularly nursing) healthcare professionals: its availability is viewed as a driving force behind the provision of disproportionate care that leads to moral distress. However, these are only apparent causes; the underlying causes relate to the ethical climate within the unit—the dynamics that occur between individual healthcare professionals and the organisational structures within which they work.

Despite studies acknowledging that moral distress occurs in other healthcare disciplines,[4] nurses remain the main focus of empirical research. Molloy et al[16] justify this imbalance by stating that nurses are the frontline workers, representing the largest number within the healthcare team. The negative impact of moral distress on work engagement[21] and job retention[22] provides further justification. Yet the prevailing attitude is that nurses are particularly vulnerable 'because of the nature of nursing as a moral endeavour, the intimacy of the nurse-patient relationship, and the role of nurses'.[4] Despite efforts in collaboration, physicians are still depicted as upholding the 'goals of "saving life" and "furthering the advancement of science" often support[ing] continued technologic interventions beyond the comfort level of the nurse', and 'causing harm instead of providing comfort and dignity to patients at the ends of their lives'.[4] Nurses are thus presented as victims of the 'aggressive care': the physician is the perpetrator, responsible for the treatment plan. Medical literature, in contrast, tends not to use the term moral distress. Rather, the terms 'dilemma' or 'ethical confrontation' are used despite clear examples of constrained responses to moral judgements.

Such distinctions between nursing and medical staff are unwarranted. Solomon et al[11] found 38% of critical care physicians and 48% of nursing staff reported acting against their consciences. Trotochaud et al[19] also found no statistical difference between physician and nursing moral distress within critical care staff. This is despite Trotochaud et al using the MDS-R, a scale that is a more concise (21 items) version of Corley's original MDS[23] that measures the frequency and intensity of moral distress. The MDS-R was designed for both multivariate research and clinical use, and involves six parallel versions (adult/paediatric populations, and for nursing, physician and other healthcare professionals).[24] Yet its conceptualisation of moral distress appears limited and potentially underestimates the degree of moral distress experienced by physicians. Its poorer reliability in physicians[24] limits comparisons between healthcare professionals. As the multifaceted causes of moral distress are further delineated, the instrument will need to be revised to increase its sensitivity for different providers and settings.[9]

An emphasis on ethical climate[7 15 20] rather than on psychological aspects of moral distress has been a relatively recent advance in moral distress literature. Sauerland et al[7] used Olson's 26-item Hospital Ethical Climate Survey (HECS) to measure how hospital nurses perceive their work setting, by addressing five factors reflecting nurses' relationships with peers, patients, managers, physicians and the hospital.[25] Though the nurses described their environment as moderately ethical, the HECS statement reflecting involvement in treatment decisions was among the lowest-scoring items. This implies that where there are ethical concerns, nurses may feel unable to voice their views as they see themselves as bearing little influence, contributing to moral distress.[7]

It is noteworthy that empirical research focusing on nursing staff frequently calls for increased collaboration, yet the vast majority of these studies fails to consider the ethical climate or capture the perspectives of other healthcare professionals. Wall et al's study[20] is therefore important in providing a multidisciplinary perspective, 'revealing that organisational characteristics impact all healthcare providers, although they do so in different ways, depending on relative organisational power, position and role.' Wall et al acknowledged that 'having a voice and being heard were common needs.' Importantly, parental views (and their moral distress) were notably absent from the discussions of included studies (though parental moral distress was not sought in the search strategy).

Education has been an alternative focus for potential interventions with very mixed results. Some studies suggest that further education exposes staff to additional ethics education that increases the participant's moral sensitivity and thus predisposition to moral distress.[7 26] Conversely, it may be reasonable to think that improved education regarding the outcomes of patients, the degree of uncertainty of certain conditions and appropriate pain control in intensive care patients leads to empowerment to voice and articulate concerns in a constructive manner. Lawrence et al[21] found a relationship within NICU nurses between education level and Critical Reflective Practice (CRP)—defined by the authors as 'being mindful of self within or after professional practice situations', for example, reflecting on moral sensitivity and understanding personal motivations for action. However, this relationship was not evident in the PICU or medical intensive care unit (MICU) populations. Sauerland et al found that MDS scores were lower in paediatric/neonatal nurses despite 77% holding a bachelor's degree or higher compared with slightly more than 50% in the adult setting. The majority of researchers, however, have reported that there was no relationship between the experience of moral distress and characteristics such as age, religion, level of education and marital status.[4]

Clinical acumen, and not just years worked or degree obtained, must also be considered in assessments of education. Janvier et al[12] examined the impact of clinical knowledge that influences assessment of a patient's 'best interest'. Residents and nurses who were inaccurately pessimistic about neonatal outcomes had higher thresholds for resuscitation at the limits of viability. However, while the pessimistic residents experienced fewer ethical confrontations, pessimistic nurses conversely experienced more. Improving knowledge of outcomes to combat moral distress has been relatively underexplored in a literature that has focused on hierarchical interactions. Yet in a field where there is genuine uncertainty, subjective assessments of pain and suffering and a duty to progress medical knowledge and practice, it is unreasonable to expect that education alone is sufficient to overcome moral distress.

The key may be in understanding how experiences of moral distress change with respect to time and in response to the evolving dynamics of the patient, his or her family and the institutional climate—yet no longitudinal studies directly examining moral distress were identified. Epstein has proposed at a theoretical level that moral distress for an individual will increase with repeated exposure to distress (the 'crescendo effect').[2] Conversely, it may be hypothesised that continued exposure leads to desensitisation and thus reduced moral distress. No published studies support either view: there is no association between years of practice and moral distress. Nor can it be assumed that years of practice equates to exposure to morally distressing situations. Healthcare professionals for whom moral distress has a highly negative impact may abandon the intensive care unit (ICU) setting to provide care in less morally challenging environments.

It is conceivable that the degree of moral distress on a unit would vary with time, depending on the cases in the unit, how firmly moral views are held by individuals and how responsive the ethical environment is to the distress. Thus the Lee and Dupree study,[18] which interviewed participants after the death of a child (mostly following redirection of care), may underestimate the degree of moral distress experienced by staff at other points in time. As moral distress is generally experienced during

perceived overtreatment rather than undertreatment,[13] the study may be missing the patients who caused the greatest moral distress in the unit—for example, patients kept alive 'at all costs' as per the families' wishes. Some of the participants describe disquiet, if not moral distress, at some point prior to the patient dying. The death of the patient had however brought resolution to the distress—thus Lee and Dupree conclude that participants 'ultimately' felt that the team had done "right" by the child and family' (emphases added). Evaluating the nature of moral distress longitudinally may provide valuable insights into the true intensity and frequency of moral distress in ICUs as well as highlight the impact of changing dynamics and interactions within the ethical climate.

Implications

Despite variations in definitions of moral distress, a commonly held conclusion from the above studies is that rather than trying to define moral distress we should be looking to study interventions[7 18 21 27] that alleviate moral distress, especially for nurses. For example, Cavaliere recommends that we 'specifically test actions and find solutions that will prevent futile care as well as to protect and defend nurses from the pain of powerlessness and participation in such care that appears to be harming the patient'.[4] This step towards interventions may be somewhat premature for, as is evident in this review the inclusions of all stakeholders' perspectives remains lacking. Even studies addressing ethical climate, for example, Sauerland et al,[7] have not adequately looked at the interplay of other healthcare professionals nor the perspectives of families within the same environment. Interventions based on a singular or limited perspective have the potential to decrease the impact of collaboration and exacerbate the differences between healthcare providers. A mutual understanding of perspectives from all stakeholders is required to improve the ethical environment and ultimately decrease moral distress for all members of the healthcare team, including the parents.

With the advancement of medicine, it is difficult to imagine eliminating moral distress altogether. It must be asked whether, in our pluralistic world with uncertain outcomes, the elimination of moral distress is even desirable.[28] The answers to some difficult ethical dilemmas are often not black and white and should cause some distress and unease in both healthcare professionals and parents. It is hard to navigate between 'doing too much' and 'not enough'. How much moral distress is necessary, so that we continue asking ourselves the right question and challenging ourselves when there are new treatments available? If some moral distress is necessary for progress, how do we deal with this 'useful baseline moral distress' or healthy ethical confrontation, to be able to live with 'moral peace' for all involved?

Limitations

The variety of mixed methodologies and populations makes direct comparisons of studies and generalisation of result difficult. However it is valuable in demonstrating the scope of research in this area. Parental perspectives are an important component of end-of-life discussions but are beyond the scope of this discussion.

CONCLUSIONS

Moral distress continues to affect the care of paediatric and neonatal intensive care patients. Empirical data on the moral distress of multidisciplinary populations remains sparse within NICUs and PICUs. Meaningful dialogue has been hindered by differing expressions of moral distress across healthcare professions and a lack of understanding of how moral distress changes with time. Further research is required to elucidate (or investigate) the perspectives of all team members, including parents, at various points along the decision-making process to enable effective interventions against 'unhelpful' moral distress.

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